## UPDATED BACKGROUND INFORMATION FOR DECEMBER 2, 1998 HEARING ON STEM CELL RESEARCH

Thursday, November 19, 1998

## LOGISTICS:

- Hearing. The hearing is scheduled to begin at 9:30 a.m., December 2, 1998, in 192 Dirksen Senate Office Building, before the Senate Labor, HHS, Education Appropriations Subcommittee (Senator Specter (R-PA), Chairman). Dr. Varmus has been asked to testify on the first panel. The second panel will include the investigators Dr. James Thompson, Wisconsin Regional Primate Center, University of Wisconsin, Madison, WI; Dr. John Gearhart, Johns Hopkins University School of Medicine, Baltimore, MD; and Dr. Michael West, Chief Executive of Advanced Cell Technology of Worcester, MA. The third panel will include Dr. Arthur Caplan, Director, Center for Bioethics, University of Pennsylvania; another ethicist from a group representing the Christian Coalition or another conservative ethics group; and possibly a representative of the Geron Corporation.
- Testimony. At the November 10 briefing of Congressional Staff conducted by Dr. Skirboll, Bettilou Taylor indicated that she would expect Dr. Varmus' testimony to address the following: "What is the science?" Why is this a breakthrough? Why should it not be Federally funded? If it's a breakthrough, why not fund it with Federal dollars? (A question she said that both Senators Specter and Harkin were interested in.) What are the scientific and health-related possibilities? What are the ethical and medical considerations? Could we make other research advances more quickly as a result of this research? What are the Federal policies involved with this issue? The Department has been told that it may not expect to receive the draft for clearance until November 24 or 25. With many staff on leave for the holiday, Roger McClung indicated that it may not be cleared until the day before the hearing. We would hope to fax a copy to Bettilou Taylor, Clerk, Senate Appropriations Subcommittee on Labor, HHS, and Education, as soon as feasible. OLPA will copy and transmit copies of the statement to the Subcommittee as soon as it is cleared.
- Anticipated Member Attendance and Questions at the Hearing. Conversation with the Appropriations Subcommittee staff indicate that calls to staff to determine attendance and anticipated questions will likely be unproductive before Monday, November 30. However, OLPA will be making calls beginning Monday, November 23.

## BACKGROUND:

• Briefing with Senate Appropriations Staff. On November 10, 1998, at the request of Ellen Murray, Associate Appropriations staff to the Senate Labor, HHS, Education Appropriations Subcommittee, for the Ranking Minority Senator Tom Harkin (D-IA), Dr.

Lana Skirboll, Associate Director for Science Policy, provided a briefing for a group of majority and minority appropriations staff, on the recent work on stem cells published in <u>Science</u>. The briefing included Bettilou Taylor, Clerk, Jim Sourwine, professional Staff, and Mary Dietrich, Senate Appropriations Subcommittee on Labor, HHS, Education; Mark Smith, staff to Senator Mack (R-FL); Ellen Murray and Sabrina Corlette, staff to Senator Harkin (D-IA); Kevin Mathis and Allison Dekorskie, staff to Senator Specter (R-PA); and Pat DeLeon and Nancy Gilmore, Staff to Senator Inouye (D-HI).

- Questions. The major questions which arose from the discussion with Senate staff on November 10 were the following:
  - Would the cell lines developed from Dr. Thompson's work be able to be used without violating the Human Embryo Research (HER) ban? When did NIH make the request for a legal opinion on this issue? Ms. Taylor indicated that Senator Specter could be counted on to pursue the issue of the derived cells, and DHHS would be advised to have a response, given the lead time in advance of the hearing.
  - Could the Committee have a copy of the consent form (or a blank consent form) of the type used by Dr. Thompson for the "spare embryos" that were used in the experiment? Dr. Skirboll stated that NIH does not have that information, but has alerted Dr. Thompson that the staff had asked about it.
  - Has NIH ever funded HER research? It was explained that the possibility of request for support for this type of research led to the creation of the Human Embryo Panel and its report. NIH has never funded this type of research.
  - What is the anticipated pace of this research? How much funding could be infused? What is the commercial potential? How soon could some of the benefits be available if the work were to proceed? Because there are so many possibilities for commercial applications, it was explained this could become a reality in our lifetime, certainly in that of our children. No more specific parameters could be placed on this.
  - How much did the research described cost to conduct? Dr. Skirboll stated that NIH does not know the answer.
  - It was also mentioned that Dr. Varmus might expect questions on his statement in the New York Times, saying that he was sorry NIH couldn't fund this research.

## **Meeting Convened by OSTP:**

OSTP has convened a meeting to discuss issues related to the recent "stem cell/cloning" research. The meeting is confirmed for Monday, November 23, 4:30 - 5:30 P.M. in the Old Executive Office Building, Rm. 422. The participants will be as follows: Dr. Varmus, Dr. Skirboll, Dr. Lane (OSTP), Chris Jennings (DPC); Dr. Raub (HHS). A representative from the Vice President's Office may be invited as well.

**Attachments:** Press articles on the stem cell research and the SCNT research.